

Articles

Making interactive decision support for patients a reality

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ABSTRACT

Interactive decision support applications might help patients to make difficult decisions about their health care. They lie in the context of traditional decision aids, which are known to have effects on a number of patient outcomes, including knowledge and decisional conflict. The problem of restricted uptake with decision aids may be addressed by interactive applications, particularly if associated

with health information websites. We suggest that there may be an impact on the doctor–patient relationship and that this presents a number of opportunities. However, there are ethical challenges such as information bias and commercialisation.

Keywords: decision aid, health information websites, interactive decision support

Introduction

Innovation is needed in the way in which health information is presented to patients. Traditional formats – one-way time-pressured speech by physicians and text-rich documents – are unable to accommodate the demands by patients for autonomy in the selection, processing and integration of information.¹ This is particularly so when the information is used by patients to make difficult decisions about their health. Interactive decision support may be of help: it involves the use of interactive computer technology to present a variety of options to patients, tailored to their specific needs. To a certain extent this is a development of existing decision aids which have, to date, been mostly linear documents and videos.² In common with decision aids, a broad range of health conditions are being addressed by interactive decision support applications which are also being developed internationally. However, they also share the problem of limited patient uptake: possibly a consequence of access difficulties. This may be addressed by the

development of health information websites. It is currently unclear what effect these applications will have on enhancing decision support and also on wider issues such as the doctor–patient relationship. It is almost certain, however, that specific ethical challenges will emerge, such as the commercialisation of decision support. This paper considers some of these issues; it is based on a literature review of ‘interactive decision support’ involving three electronic databases.

Interactive decision support applications

A variety of terms have been used to describe interactive decision support applications. In many respects this is a reflection of their different levels of technological sophistication. The earlier applications were described as *interactive videos*:³ they presented only limited opportunities for patient interactivity. The more recent products have been described as

interactive decision aids:^{4,5} in these, multimedia technology is used to present information and patient experiences in a range of formats; the user also has greater freedom to navigate through the program and choose the most relevant information.⁵ The term *decision explorer* may be used for future applications which may present a series of different outcomes or *futures* to the user. The range of medical issues addressed by these applications varies from hormone replacement therapy⁶ to the treatment options for early-stage breast cancer.⁷ Chronic diseases – where there are a number of different treatment options – are frequently encountered subjects: ischaemic heart disease particularly so.^{3,8} Surgery represents potentially one of the most difficult decisions to face patients and this is reflected in the interactive decision support available; for example, back surgery⁹ and the treatments, including surgery, for benign prostatic hyperplasia.⁴ Most of the applications have been produced in North America; indeed one institution, the Foundation for Informed Medical Decision Making, has created a series of web-based programs and videotape decision aids on a wide range of topics, including breast cancer, ischaemic heart disease and the prostate-specific antigen (PSA) test.¹⁰

There may be a role for these applications in situations where communication has traditionally been difficult: an interactive CD-ROM to reduce adolescent substance abuse had positive results in terms of the intention to take drugs.¹¹ Furthermore, countering the argument that these are mainly interventions for an educated, IT-literate minority, a multimedia breast cancer education intervention was recently used with low-income 'Latinas' women in the USA: 40% of the women who subsequently undertook mammography attributed their decision to the intervention.⁵

Some of the interactive decision support applications have been evaluated in trials. A variety of outcomes have been considered, including knowledge,⁸ subsequent decision/behaviour,⁷ anxiety,⁴ satisfaction with decision,⁹ and uncertainty or decisional conflict.⁴ At present the effect on these outcomes is inconclusive as there are only a few evaluations. From the wider context of decision aids – mostly non-interactive – it is known, however, that there is a consistent effect on some of these outcomes: knowledge, for example, is generally improved and decisional conflict reduced.² Nonetheless there is clearly a need for further evaluations of existing and future applications. Such information may help the development of specific quality criteria for interactive decision applications. Existing criteria such as CREDIBLE² encompass all decision aids: whilst they have an important role, they may only allow limited scrutiny of certain issues, particularly those related to human–computer interaction. In common with other decision aids, however, the uptake and utilisation of interactive decision support applications

has, to date, been very limited. The barriers to implementation are unclear but may relate to the costs and relative inaccessibility of these applications.¹²

The role of health information websites

The internet may help in the dissemination and implementation of interactive decision support. Its dramatic growth offers patients a range of opportunities: information is presented in a range of media and patients can share their experiences in online communities. The difficulty that both governmental and non-governmental health organisations face is that they have little or no control over the information accessed by patients; search engines such as *Google* rapidly provide details on a multitude of websites in response to minimal information from the user. Cynics may argue that the issue for governments is that of control, but clearly an unregulated field leaves patients exposed to online information of potentially suspect quality. Partly as a consequence of these fears and also due to the recognition of the opportunities for public health improvement, a number of government-backed health information websites have been developed worldwide: *Canadian Health Network* (Canada),¹³ *Healthfinder* (USA),¹⁴ *Healthinsite* (Australia)¹⁵ and *NHS Direct Online* (UK).¹⁶ They have also been developed by non-governmental organisations, particularly in the USA, for example *Kaiser Permanente*¹⁷ and *mayoclinic.com*.¹⁸

Most health information websites do not develop all the information themselves. The trend seems to be towards devolving this process to recognised organisations such as charities or academic institutions. These collaborative organisations earn the right to provide the information by typically fulfilling a number of quality criteria. The *Canadian Health Network*, for example, demands that the authors of the information are Canadian, work for non-profit organisations and disclose any conflicting interests; furthermore the information must be 'credible, usable, relevant, appropriate and up to date'.¹³ By devolving the content development, producers of health information websites are able to avoid micromanagement of the information. Consequently, they are able to respond quickly to technological innovations such as video/multimedia; they are also in a position to enhance the interactivity of the websites.

There are currently few opportunities for patient interactivity: information is generally obtained in response to specific search headings or phrases. Ideally, patients should be able to ask complex health questions and to contextualise the information to

their own background and needs. Nonetheless there are some encouraging signs: *Healthinsite*, for example, now has a facility known as 'Personal Profile' where relevant information can be stored; patients also receive emails to notify any changes to this information.¹⁵ Enhanced interactivity could make these health information websites the ideal setting for interactive decision support. In other words there could be digital convergence between health information websites and interactive decision support applications. Digital television would facilitate this as the multimedia content would be particularly suited for interactive channels. It will therefore be interesting to note the development of the proposed UK NHS digital television service.

The impact on health care

Interactive decision support cannot be considered in isolation from the more traditional aspects of health care. Patients will continue to seek advice and treatment from doctors and nurses, but they increasingly do so armed with information from an online interactive application. Conversely, the clinician might direct the patient to such an application. Both parties have much to gain: Molenaar *et al* found that both surgeons and patients were positive in their response to an interactive CD-ROM for breast cancer treatment.⁷ However, the effect of interactive decision support on patients' treatment decisions is unclear and may well depend on the application and subject in question. In the case of the breast cancer CD-ROM, no effect on treatment decision was found.⁷ However, an interactive video programme on the use of back surgery, for example, found reduced rates of surgery in the intervention group.⁹ Future developments could also see integration between interactive decision support and patients' health records. For example, patients might want to use an interactive application to help decide on cardiovascular preventative therapies. For this they might need their latest blood pressure and body mass index reading, both of which could be accessed from their health records. The development of electronic health records easily accessible to patients could enable this.

Ethical challenges

In common with other ehealth applications, the implementation of interactive decision support will present a number of ethical challenges. These have

been defined by Parker and Muir Gray in terms of access to information, access to treatments and commercialisation.¹⁹ Firstly, the information provided in interactive decision support applications is clearly open to a host of potential biases: a pharmaceutical company could, for example, support an application to help patients decide on whether to take one of its drug products. Furthermore, these products could become obtainable from the internet, raising the second issue of access to treatments. Another example of this could be a decision support application for patients to decide on whether to have a genetic test, arranged via the internet. Finally, there is commercialisation, which in many ways underpins the other two issues. The increasing costs involved in developing sophisticated interactive decision support may well become prohibitive for government health organisations and charities, and this would leave the field open to commercial organisations such as pharmaceutical companies. Whilst they could afford to develop these applications, clearly it would need to be a commercial proposition: it is inevitable, therefore, that in some way their products would be linked to the interactive decision support. Addressing these challenges will plainly become a pressing issue for governments and health organisations; however, there needs to be caution against over-regulation in a field where innovation and development are vitally important.²⁰

We suggest that the solution lies with health information websites guiding patients to interactive applications produced by recognised providers. This recognition would involve a rigorous quality assurance process but would avoid the micromanagement of the individual applications. We believe this to be an eminently feasible vision as decentralised quality assurance is already a feature of health information websites. Furthermore, it would encourage a healthy discourse between governments and providers during both the development and implementation of these applications. Interactive decision support could then indeed become a reliable and high-quality reality for patients.

Future developments

Interactive health communication applications (IHCAs) are here to stay, and in ever increasing numbers. They will have a significant effect on the doctor-patient relationship (see Figure 1).²¹ Many of the innovations are occurring in the USA, and are being driven by commercial considerations. The health policy and research community have a responsibility to examine their effects on equity of access to information or

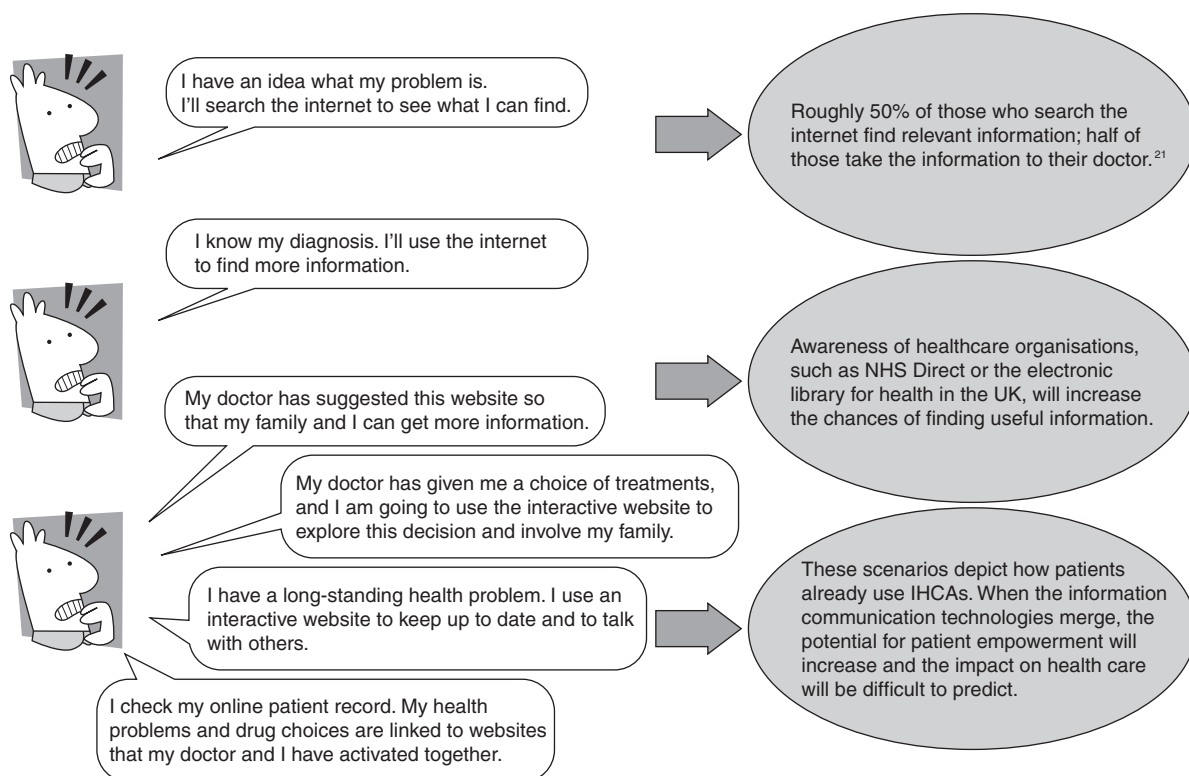


Figure 1 Effect of interactive decision support on the doctor–patient relationship

treatments; consider problems of quality control; and provide data on the effects of IHCA's on health outcomes, health service utilisation and the doctor–patient relationship. Analysis of the effects of IHCA's on the nature of professional–consumer interactions and responsibilities in healthcare decision making are required. In addition, we need to evaluate how the effects of these technologies may differ from or enhance existing innovations such as decision aids. In particular, we need to assess whether IHCA's (through their availability and so on) can overcome the barriers that currently limit the integration of decision aids into healthcare decision making.

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CONFLICTS OF INTEREST

The authors are developing an interactive decision aid for PSA testing.

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